Neutral Citation Number: [2023] EWCOP 2

Case No: 14028191

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 19/01/2023

Before:
THE HONOURABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION
- -

Between:

NHS SURREY HEARTLANDS INTEGRATED CARE BOARD

Applicant

- and –

JH

Respondent

- -
- -

Miss Emma Sutton (instructed by **Hempsons**) for the **Applicant**
JH (appearing as a **Litigant in Person**)

Hearing dates: 20th December 2022

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

.....

THE HONOURABLE MR JUSTICE HAYDEN

MR JUSTICE HAYDEN:

1. This is an application brought by NHS Surrey Integrated Care Board ("the ICB"), in respect of the respondent, JH. The ICB are represented by Miss Sutton who seeks a declaration pursuant to section 26(4) of the Mental Capacity Act 2005 ("MCA 2005") that JH made an advance decision on 10 December 2017 which is valid and which applies to any invasive test or treatment (including life sustaining treatment). Further and for the avoidance of doubt, the draft declaration seeks a recording *"that a person does not, therefore, incur liability for the consequences of withholding such tests or treatment from JH"*. JH attended the hearing by telephone. Dr W, who is employed within the ICB, carried out an assessment of capacity on 28th November 2022 which concluded that JH had capacity to conduct these proceedings. I agree with the analysis of that assessment which entirely accords with my own impressions of JH. JH had not instructed solicitors. He did not seek any adjournment to do so, though the question was raised with him. He was plainly anxious for proceedings to conclude without any further delay.

2. JH was born and grew up in Reigate in Surrey. He is one of two children. He attended a local mainstream school, although he spent much time away from it due to gastrointestinal pain and discomfort which was to plague him for the rest of his life. As a child and later as a young person, JH was seen by a variety of doctors. He was also investigated for growth delay which resulted in his short stature. He was given hormone treatment. He spent a great deal of his childhood attending hospital to be tested for a variety of conditions. In his evidence to me, he was clear that at no point did he ever submit to a colonoscopy or gastroscopy. Such investigations were considered necessary and appropriate by his treating clinicians then, and by Dr W now, to enable direct visualisation of the bowel and to allow biopsies to be taken to facilitate any diagnoses of a further range of bowel conditions that may be responsible for his symptoms. It is very clear from the evidence I have read and what from what JH has told me directly, that these extensive investigations of his childhood which necessitated such incessant hospital involvement has left him profoundly anxious and he is now entirely unprepared to attend hospital. Additionally, JH is deeply resistant to any form of invasive medical treatment.

3. JH was diagnosed with Asperger's Syndrome in 1995, age 16 (now recognised as Autistic Spectrum Disorder). His doctors also identified that JH had a phobia of hospitals, largely triggered by the background I have just set out. JH has had, if I may say so, the enormous advantage of having a General Practitioner, Dr W, who has been absolutely dedicated to his care, above and beyond professional duty or obligation. JH rarely leaves the house these days, I am told, apart from to buy cigarettes or to pay his household bills. He doesn't have any internet access and he is extremely cautious about using his central hearing. Dr W has told me that the house is frequently very cold when he visits.

4. Dr W first became involved in JH's care, when he became his patient, in 2009. Having heard evidence from both of them today, it is clear that they enjoy a convivial relationship and there is obvious mutual respect. Dr W calls into JH's flat every couple of months, for about an hour, to check up on him. He has been doing that, broadly speaking, since 2009. The abdominal pain JH complains of has particularly, as time has gone by, resulted in very poor nutritional intake. He is now deficient in the full gamut

of vitamins and he is probably anaemic. I note that in 2009 Dr W recalls that JH was at that stage eating food in very small amounts and following a restrictive diet, but as the years have gone by, and now for some considerable time, JH has only been consuming Fortisip high-calorie drinks and mineral water.

5. I am told by Dr W that JH is noticeably and visibly undernourished and emaciated, weighing in the region of six stone. In his evidence JH told me that he took one Fortisip drink a day, and sometimes aimed to take two. I am sure that JH gave that evidence believing himself to be accurate, but there was uncertainty in his evidence which left me feeling that there were perhaps days when he does not drink even one bottle of Fortisip. Dr W confirmed that the Fortisip drink contained 800 calories or thereabout and that is manifestly not enough to keep him well, or indeed, ultimately alive. Although JH happily meets with Dr W, he refuses to be weighed and whilst he understands the range of investigations Dr W would like to put in train, he maintains his refusal. When he was last weighed, now as long ago as 2017, he weighed 40.4kg (6 stone, 5 pounds). His body mass index (BMI) was 14.5. A healthy BMI for adults is between 18.5 to 24.9. Based solely on his physical appearance, Dr W estimates JH as having a significantly lower BMI than that last recorded.

6. Although JH has declined virtually all forms of health monitoring, he has permitted Dr W to take blood tests. Despite his physical deterioration, those blood tests were, until recently, broadly within normal range but are now deranged, indicating multiple vitamin deficiencies. JH has not been vaccinated against either Covid-19 or flu. The reasons he gives Dr W are that he very rarely leaves the house. He does however receive visitors and occasionally goes out. Dr W notes that given his poor health, JH would be at very high risk were he to contract a respiratory virus. In his written statement, filed within these proceedings, Dr W observed:

> *"It is my view that [JH] could die at any time and it is inevitable that his life is going to end sooner than it otherwise would if he continues with such limited nutritional intake. Although [JH] recognises this, and I do not doubt his understanding, he has no desire to investigate the causes of his abdominal pain or change. [JH] believes that he has made a valid and capacitous advance decision to refuse any investigations and therefore professionals should leave him alone and respect his choices. The prospect of these wishes being overridden causes him significant anxiety."*

7. The application has been brought before me today, on 20th December 2022, because there is a real risk that JH may not survive the Christmas period. The risk is real in the sense that if he is exposed to infection, he does not have the physical stamina or strength left effectively to resist it. Miss Sutton submitted that whilst Dr W considered that it was feasible that JH had made a valid advance decision in 2017, a court determination was requested due to the stark consequences to JH if investigations leading to potential treatment did not take place, which would include his premature death. The need for clarity was particularly important as there were differing views amongst clinicians as to whether JW had capacity to make the advance decision in 2017.

8. Initially, I had formed the impression that JH had led something of a reclusive life, but in fact, it is clear that he sees his family his son, mother and daughter (in particular) on

a very regular basis. They are all and each of them hugely important to JH. He told me that his daughter, aged 20, would move to live with him in his flat if she could, but that the terms within the tenancy agreement did not permit that possibility. She does, however, call to see him most days and stays for lengthy periods. This, of course, means she presents a risk of infection to JH, at a time when respiratory viruses are prevalent. It is with this primary risk in mind that the ICB have sought the declaration that they do. There is a secondary risk, namely that as time goes by, JH's wholly insufficient nutritional intake will compromise his immune system and metabolic system, which will itself cause his death.

The legal framework

9. The Suicide Act 1961 decriminalised the act of suicide, which is defined as the act of intentionally ending one's own life. However, whilst Section 1 abrogated suicide as a crime, Section 2(1) provides that a person who aids, abets, counsels or procures the suicide of another, or attempt by another to commit suicide, shall be liable on conviction on indictment. This offence of complicity in suicide creates a situation in which an accessory may incur liability when the principal does not commit an offence. It is a challenging backdrop to the facts of cases like this one and, no doubt in part, the reason that the ICB seek their second declaration i.e., *"that a person does not, therefore, incur liability for the consequences of withholding such tests or treatment from JH"*. It is important to emphasise, however, that there is no obligation on a patient, who has decision-making capacity, to accept life-saving treatment. Doctors are not obliged to provide treatment and, perhaps more importantly, are not entitled to do so in the face of a patient's resistance. This reflects a mature understanding of the importance of individual autonomy and respect for human dignity.

10. As noted by Lord Brandon in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1:

> *"a doctor cannot lawfully operate on adult patients of sound mind, or give them any other treatment involving the application of physical force ... without their consent', and if he were to do so, he would commit the tort of trespass to the person"* [55].

11. As Lord Goff later observed in *Airedale NHS Trust v Bland* [1993] AC 789 at [864]:

> *"... the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so".*

12. The right to self-determination was expressed by Judge LJ (as he then was) in *St George's Healthcare NHS Trust v S* [1999] (Fam) 26:

> "*Even when his or her own life depends on receiving medical treatment, an adult of sound mind is entitled to refuse it"*

13. Baker J (as he then was) applied these principles in the stark situation of an individual who declines hydration and nutrition: *An NHS Trust v* [2013] EWHC 2442 (COP) at [30]:

> "*There is no doubt that this principle applies in the context of choosing whether to refuse food and drink (see, for example, Secretary of State for the Health Department v. Rob [1995] 1 All ER 677 and A Local Authority v. E and Others [2012] EWHC 1639) ….*"

14. The consequence of Section 26 of the Mental Capacity Act 2005 (which sets out the effect of an advance decision), applied to the current facts, is that if JH made a valid advance decision on 10th December 2017, that has effect as if he had made it at the time when treatment falls to be considered.

15. The relevant parts of the MCA 2005 require to be set out in full:

> *"Advance decisions to refuse treatment*
>
> ***24 Advance decisions to refuse treatment: general***
> *(1) "Advance decision" means a decision made by a person ("P"), after he has reached 18 and when he has capacity to do so, that if—*
>
> *(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and*
> *(b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.*
>
> *(2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms.*
> *(3) P may withdraw or alter an advance decision at any time when he has capacity to do so.*
> *(4) A withdrawal (including a partial withdrawal) need not be in writing.*
> *(5) An alteration of an advance decision need not be in writing (unless section 25(5) applies in relation to the decision resulting from the alteration).*
>
> ***25 Validity and applicability of advance decisions***
> *(1) An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time—*
>
> *(a) valid, and*
> *(b) applicable to the treatment.*

(2) An advance decision is not valid if P—

(a) has withdrawn the decision at a time when he had capacity to do so,
(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or
(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

(3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.
(4) An advance decision is not applicable to the treatment in question if—

(a) that treatment is not the treatment specified in the advance decision,
(b) any circumstances specified in the advance decision are absent, or
(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

(5) An advance decision is not applicable to life-sustaining treatment unless—

(a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and
(b) the decision and statement comply with subsection (6).

(6) A decision or statement complies with this subsection only if—
(a) it is in writing,
(b) it is signed by P or by another person in P's presence and by P's direction,
(c) the signature is made or acknowledged by P in the presence of a witness, and
(d) the witness signs it, or acknowledges his signature, in P's presence.
(7) The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.

26 Effect of advance decisions
(1) If P has made an advance decision which is—
(a) valid, and

(b) applicable to a treatment, the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.
(2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.
(3) A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.
(4) The court may make a declaration as to whether an advance decision—
(a) exists;
(b) is valid;
(c) is applicable to a treatment.
(5) Nothing in an apparent advance decision stops a person—
(a) providing life-sustaining treatment, or
(b) doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court"

16. The advance decision was made in December 2017. It was manifestly constructed carefully and, I was told, with the assistance of JH's family and friends. The date on the document is muddled, but the rest of the detail is pellucidly clear. The template for the decision was based on a document downloaded from the internet from an organisation named "Compassion in Dying". The document is structured around the relevant provisions of Section 24-26 inclusive of the MCA 2005. In his statement, Dr W records:

> *"I note that the advance decision is very detailed and it is factually correct that [JH] has been unwell since he was a child and he has seen many specialists over the years. The reasons given by [JH] for refusing treatment are also wholly consistent with what he had always said about his health and abdominal pain. I am satisfied that [JH] does understand that refusing investigations and continuing with his current nutritional intake is likely to result in his premature death."*

17. In the Decision, JH makes careful provision about the circumstances in which he would wish to refuse treatment, including brain injury, diseases of the central nervous system and terminal illness. The key passage, for the purposes of this application, is set out under the heading "Refusing Treatment In Other Scenarios". This has been written by hand by JH and typed up, by a friend, and copied verbatim. It reflects something of JH's personality and a thought structure which can be traced through the documentation over the years:

> *"If my health deteriorates or if I should collapse and not have capacity to make decisions:*
> *I do not wish to attend any hospital/ medical setting.*

I do not wish to have treatment which involves inserting tubes into my body, operations, x rays or MRI scans. I am willing to have bloods tests at home and to be weighed. I wish to continue with diabetic treatment and medicines around that.
I wish to have involvement with G.P, G.P practice nurses, Social Worker and Dietician but no involvement from other team members.
I do not wish to have any unannounced visits from the Dietician. If the Dietician attends, I wish for the appointment to be pre-arranged and for a family member or my advocate to be present.
I do not give permission for practitioners to be looking back through historical case notes.
I do not wish for Multi-disciplinary meetings to be carried out without my knowledge and if a meeting needs to be carried out about my care, I wish to be fully informed beforehand.
I wish to be fully informed of any discussions between practitioners about my case.
I would like to be included by telephone or if I am unable to be present or on the phone, I wish to receive an agenda beforehand and written notes to inform me what has been discussed.
I do not wish to be kept in the dark about my care or for practitioners to talk about my care without fully informing me.
I do not wish for any assessments to be carried out on me without full written information regarding the assessments.
I do not wish to discuss my history going back to my childhood treatment.
I do not wish to make on the spot decisions about my care. The best way to enable me to make a decision is to provide the information and then give me time to think about the decision when I don't have the pressure of time restrictions"

18. As Miss Sutton submits, the real issue of concern, in terms of adherence to the statutory formalities, arises from the provisions of Section 24(1) MCA 2005 and, in particular, whether the Decision was made by JH at a time (December 2017) when he had capacity to do so. Dr W considered that JH was likely to have had the capacity to make the Advance Decision on 10th December 2017, for the reasons I have set out above.

19. It is important to record that a capacity assessment undertaken in 2017 also concluded that JH had capacity. Later, clinicians wavered about the correctness of that 2017 assessment. It is necessary, once again, to emphasise that the MCA erects a presumption of capacity as a vital safeguard to protect adult autonomy. It is also important to reiterate that an individual's capacity to take decisions does not require those decisions to be, objectively, wise.

20. Having heard his evidence today, having considered the advance decision document in detail, and having also listened carefully to the evidence from Dr W, who I have found to be impressive, both as a doctor and a man, I am entirely satisfied that JH had the capacity, in December 2017, to make decisions regarding the refusal of his medical treatment. JH told me that what triggered the writing of this document was an encounter, at a meeting for which he did not feel that he had been fully briefed or

prepared, concerning his diet. I find his reasonings as to why he decided to draft the document entirely coherent and logical. I also find the detail of the document to be clear and rational.

21. A further important factor is that JH has talked through the document and the structure of it with his family and close friends. As I have mentioned, they have obtained the template for him and replicated, verbatim, his handwritten requests. I have no doubt at all that all of the content of the advance decision is the authentic voice of JH himself. JH told me that he had discussed the Advance Decision very carefully with his mother and his cousin, for whom he has very great regard. A friend of the family also witnessed his signature.

22. JH has long been of the belief that his stomach pains are in some way related to his Asperger's Syndrome. He has held this view for most of his adult life. It is misconceived. But many people hold irrational, inaccurate or even superstitious views in relation to their own health. In the context of Covid-19 vaccinations, a significant cohort of people do not accept or trust the accuracy of orthodox, peer-reviewed medical opinion and guidance. None of this is to be equated with lack of capacity. It is simply a facet of human nature.

23. In any event, even if JH's views might be thought to raise questions in respect of his capacity, they come nowhere close to rebutting the statutory presumption. It is also important to identify that had I found that JH lacked capacity, either in December 2017 or indeed, at the time of this hearing, I could not have contemplated a situation in which the envisaged investigations could have been forced upon him. The strength of his feelings, the consistency with which they have been held, for so many years, and his obvious distress at the contemplation of such an intrusive investigative process would, in my judgement, be brutally corrosive of JH's autonomy. It would both compromise his dignity and cause him great personal trauma. It could not be reconciled with any concept of "best interests" in the manner required by the MCA. As Miss Sutton reminds me, JH told Dr W that if the court determined that it was in his best interests to have further investigations, *"he would not undergo them willingly and would have to be physically restrained"*. He also told Dr W that *"undergoing investigations such as a colonoscopy would make him feel violated and it is not something he could tolerate"*. I emphasise that Dr W does not consider that any further investigations should be undertaken against JH's will due to the distress it would cause him. I agree.

24. JH's resistance to this type of intrusive investigation has pervaded much of his adolescence and all of his adult life. It is deep seated and rooted in trauma and indicates entirely convincingly that if he were to be compelled to be investigated in the ways contemplated, he would find that deeply traumatic indeed. I genuinely consider that he would perceive it as a violation of his body. I find his evidence, on this point, as elsewhere, to be entirely convincing.

25. I found JH, if I may say so, an interesting and engaging man. His life may be circumscribed tightly by his situation, but it is not without richness and texture. Fortunately, he has the great privilege of an attentive, kind, loving family, who bring much warmth into his life. He is a man whose interests in nature and the outdoors can find expression even within the limited confines of his own garden. His enthusiasm for birds and nature is one which he has passed onto his son. He is a keen musician. At 12

years of age, he saved up his pocket money and bought a Fender Stratocaster American guitar. It brings obvious pleasures to JH who plays it every day. He is, from what I have been told, an accomplished guitarist. He is modest about his own accomplishment, but Dr W has told me that JH has played for him and that he considers JH plays very well indeed.

26. With all this going for him, one might think JH would cling to life with all his might. In some ways he does. He makes the most out of his circumstances. He gets great pleasure from life. Ultimately, he simply cannot accept the type of intrusive investigations contemplated here, even if such investigations ultimately improved the quality of his life and extend its duration. Refusing these procedures may not be a decision that many of us would consider to be right, but as I have said, that is not what falls into question here. The court is required to protect JH's capacity to take decisions for himself both those that may be, objectively, ill-advised, as well as those that might, more generally, be regarded as wise. I do not say, necessarily, that in his circumstances this is an unwise decision for JH. It may be that the admission for investigation might be so re-traumatising for him that its impact would be profound in an entirely different but negative way. For all these reasons, I grant the declarations sought by the ICB.

27. Because JH was identified as being in immediate and obvious risk, I delivered this judgment ex-tempore. I am grateful to Miss Sutton and her team for their careful note which has enabled me to provide a full transcript of this judgment.